PENGALAMAN HIDUP KELUARGA DALAM PERAWATAN ANAK DENGAN HIV/AIDS DI KOTA CIMAHI

(Family's Life Experience in Taking Care Children with HIV/AIDS in Cimahi City)

Lina Safarina
STIKES Jend.Achmad Yani Cimahi
Email:Linasafarina.1976@gmail.com

ABSTRAK

Pendahuluan. Indonesia memiliki peningkatan pada kasus HIV/AIDS secara signifikan. Kejadian HIV/AIDS pada anak juga mengalami peningkatan. Anak yang terinfeksi HIV mudah diserang dengan masalah fisik dan psikososial yang komplek. Peningkatan isu pada keluarga dalam perawatan anak dengan HIV/AIDS. Tujuan penelitian ini adalah untuk menyelidiki pengalaman keluarga secara mendalam dalam merawat anak dengan HIV/AIDS. **Metode.** Penelitian ini menggunakan pendekatan kualitatif fenomenologi. Penelitian ini dilakukan selama bulan Juli-Agustus di Cimahi. Penelitian ini dilakukan pada keluarga yang memilki anak dengan HIV/AIDS. Metode pengumpulan data menggunakan wawancara mendalam. Analisis data digunakan untuk menjelaskan pengalaman hidup keluarga dalam perawatan anak dengan HIV/AIDS dengan analisis data Colaizi. **Hasil.** Anak dengan HIV/AIDS memiliki pengalaman berbagai masalah berhubungan dengan kemungkinan terjadinya infeksi, gangguan pertumbuhan dan perkembangan, pendidikan, kemampuan sosial dan penerimaan di lingkungan sosial. **Diskusi.** Perawat dapat memberikan informasi tentang perawatan anak dengan HIV/AIDS, memberikan dukungan pada keluarga untuk program VCT, supervisi ARV, peningkatan motivasi, kesehatan anak, kebutuhan anak untuk belajar dan bermain, dukungan keluarga untuk mengikuti program PMTCT untuk meningkatkan kualitas hidup pada anak dan keluarganya.

Kata Kunci: Anak dengan HIV/AIDS, pengalaman keluarga, kualitas hidup.

ABSTRACT

Introduction. *Indonesia has increase in cases of HIV/AIDS significantly. HIV/AIDS incidence in children is increase too. Children with HIV infection are vulnerable to physical and psychosocial problems are complex. This raises the issue of the family in caring for children with HIV/AIDS. The purpose of this study was to explore in depth the experiences of family life in the care of children with HIV/AIDS.* ***Methods.*** *The study used a qualitative approach was phenomenological. This research was conducted during the months of July-August 2012 in Cimahi. The study was conducted on families who have children with HIV/AIDS. Method of data collection study using in-depth interviews. Analysis of the data used to describe the lived experience of families in caring for children with HIV/AIDS with Colaizi data analysis.* ***Results.*** *Children with HIV/AIDS had experience a variety of problems related to the infection opportunity, growth and development disability, education, social skills and acceptance in society.* ***Discussion.*** *Nurse can give information about caring children with HIV/AIDS, give the support to family to get VCT program, ARV supervision, motivation enhancement, child health, children need to learn and play, support family to join with PMTCT program to increase quality of life of the children and family.*

Keywords: *Children with HIV/AIDS, Family's Experience, Quality of Life.*

INTRODUCTION

HIV (Human Immunodeficiency Virus) is a virus that can cause AIDS. These viruses infect humans and can cause a decrease in the immune system (immunity) of the body, so the body becomes weak to fight the infection that would cause a deficiency (lack of) immune system. Patients are vulnerable and easily affected with various diseases (Sudoyo, 2006).

To date, the ratio of AIDS cases in men and women by 61%: 39%. Although the number of cases of HIV / AIDS on men higher than women, but because of the mode of transmission is through heterosexual majority (66.95%), this may affect the transmission in women. The majority of women who have HIV/AIDS are of reproductive age (15-49 years) that is equal to 92.54%, then this raises the risk of pregnancy by HIV positive number

will increase (Ministry of Health, 2011) and cause problems the risk of HIV transmission from mother to child. Transmission of HIV from mother to child or vertical transmission (mother to child transmission) occurs through transplacenta during pregnancy, through genital fluids and blood during the birth process and through breast milk during lactation (Varleys, 1999).

HIV incidence in children are increasing with the increase in the incidence of HIV in women, according to Ministry of Health reports first quarter of 2011, the incidence of AIDS in children ranging in age from less than one year was 2.85%, of children under five as much as 1.17%, children aged 5 to 14 years as much as 1.42% and children aged 15 to 19 years as much as 3.13% for a total incidence of AIDS in children by 8.56% or ranked second after adulthood (Kemenkes R.I, 2011) RI, 2011).

The impact of HIV/AIDS is seen in children. This impact can occur in several ways (UNICEF, 2007). Children lost childhood and should not see their parents died. Globally 15 million children orphaned and or orphaned because of HIV/AIDS and less than ten percent of the support and community health services.

Health problem in children with HIV/AIDS is a failure of development of the child. In certain cases it is possible children orphaned early or an increase in health care costs were larger than normal babies. HIV-infected children had to face many challenges in his life, such as the face of loss or death of a parent, continuous adjustment to illness, and psychological health problems their parents, and their own psychological problems. This challenge will ultimately affect their growth. Thus it can be said that children infected with HIV are vulnerable to physical and psychosocial problems are complex (Nursalam, 2007).

Physically, most children with HIV did not gain weight but can also grow normally. Motor skills and mental development often lags behind normal children such as crawling, walking and talking. Along with the development of the disease, many children have nervous system problems such as difficulty walking, poor school performance, seizures, and symptoms of HIV encephalopathy (brain abnormalities). Children with HIV suffer from infectious diseases that commonly occur in children more often and more severely than uninfected children.

Children also lose the opportunity to get an education. Moreover, children living with parents with HIV/AIDS are very likely not chronic exposure to education because of the high cost of living for treatment, health care parents and children. From the aspect of play, children whose parents are chronically HIV little chance the parents will take the time to assist child when playing with his friends, even the children lose the opportunity of play due to his physical condition (Prasetyo, 2008).

Children with HIV/AIDS also bring a deep emotional trauma for his family. Parents have to face severe problems in child care, care giving so as to overcome emotional problems (Kemenkes R.I, 2011). Guardians or parents in caring for children with HIV/AIDS are very vulnerable to depression. Based on research by the Department of Psychiatry RSCM, about 40% of the child's parent or guardian HIV positive in the hospital having psychiatric disorders, in this case the depression of having to bear the problems of living in a society that is less supportive.

Family with children with HIV/AIDS may also experience discrimination during her care, including the shunned like child's play, and for the social life, child PLHIV households spend less time for exercise, reading, and join the religious group with friends and other families

METHODS

The study used a qualitative approach was phenomenological. Qualitative research was an approach to develop knowledge of research methods by emphasizing subjectivity and meaning of the experience for the individual (Brockopp, 2000). This research was conducted during the months of July-August 2012 in Cimahi. The study was conducted on families who have children with HIV/AIDS. Participants in the study were

families with children with HIV/AIDS. The definition of the family in this study was the everyday parenting, in this case the mother or guardian (if the mother has died of the world or do not care for). Determination of the participants using purposive sampling, the sample selection based on predetermined criteria to obtain information in accordance with the objectives of the study. Criteria for participants in this study were: Conditions participant families who have children with HIV/AIDS (the family was caring for the child), participants can communicate well, willing to become informants. From the data obtained from the health office Cimahi, got 6 children who have HIV/AIDS and 6 families.

Method of data collection study using in-depth interviews. Interview used semi-structured interviews with using open-ended questions shaped the interview and focus on issues or topics that will be examined in accordance with the objectives of the study.

Analysis of the data used to describe the lived experience of families in caring for children with HIV / AIDS with Colaizi data analysis. With Colaizi approach can describe the meaning of the experience through important themes (Polit & Back, 2006). There are four criteria used in the validity of the data, the degree of confidence (creadibility), dependence (dependability), transferability and certainty (Confirmability) (Satori, 2011).

RESULT

Characteristicts of Respondents

Resp. (Age)	Employment	Relationship with Children	Children with HIV/ AIDS (Age)	Child Conditions	HIV Diagnosis of Child/ Last CD4	Parents Conditions
1 (44 years)	Housewife Health	Grandma	M 4,5 years	Active	2010/ 800	Mother dead in 2011, father dead in 2010
2 (48 years)	Housewife	Grandma	A 3 years	Less active	2010/600	Mother dead in 2011 Father dead in 2010
3 (51 years)	Laundry worker	Grandma	A 6,5 years Studied at kindergarten	Walking impairment Being sick	2008/600	Father dead in 2010 Mother sick (CD4 14, syphylis +, pregnancy) Married
4 (29 years)	Selling clothes	Mother	D 3 years	Walking impairment	2010/2000	Father dead in 2009. HIV diagnosis of mother in 2008
5 (21 years)	Housewife	Mother	S 6 years Studied at kindergarten	Walking impairment	2010	Father dead in 2010
6 (32 years)	Housewife	Mother	P 5 years Studied at kindergarten	Active	2009/1300	Father negative Mother positive, 2009

The themes formed:

1) Response when HIV diagnosis:
Response when HIV diagnosis are Denial and sad
Respondents who claim to denial and sad:
" shocked, can not believe, I use syringe only once but got viruses…"

"im so sad when knew my condition…I didn't anything bad .but I got HIV…"

2) Response when knew children status of HIV
Respondents who said sadly:
" cry till 3 months..didnt believe my son has the same condition with me.."

" very sad…weight loss when I knew my grandson status…"

"…my grandson got a viruses too.. its make me sad…I'm afraid I will lost him…such as i lost my son…"

3) A complaints when caring children with HIV
The theme that formed:fatique, anxiety, cost
" Yes so fatique..specially my child have walking impairment..I am carry him everywhere..i feel so tired…"

"..fatique..specially when my condition not good or when my CD4 decrease.."

"..very fatique ..i must strong, take care my grandson with HIV, take care my husband too cause he is stroke now.., and my children got paralyzed..andim working too…"

"crying when I saw my child..worried if she get sick like fever…I'm worried she has short lived.."

" we must prepare 100 thousands every month for his medicine…its make me confuse.."

4) The efforts to handle of a complaints, the theme formed are: rest, pray, cost support

"..just take a rest, specially im pregnant now.."

"..praying hard…getting closer to the God.."

"..more diligent to pray.."

"..fortunately there is a cost support from

LSM..for treatment and medical check up.."
"..yes..my parents still help by cost support..but not often.."

5) Changes in parenting after child HIV diagnosis, a theme formed: more protective
" Yes since I knew my children sick..im more protect her..i watch everything what she done and what she need. .specials her healthy.."

"..more protect, donot let my child sick.."
..yeah, my child need extraordinary attention, spesials he has walking impaitment, I was really protect him.."

6) Openess status of children to the community, school and family, theme formed: closed
"..person who know my child status only my husband and my sister..i don't want other people know my daughter status, I have bad experience when public know my status..my friend in the office knew my status and I was fired..i will not let my child have this experience too.."

" I don't want people know my grandson status..i have bad experience with my big family.. there was celebration in my big family..all invited except me and my family..they didn't invite us because my family specially my son's HIV..so I will not let they know my grandson status.."

"..no body know…but im worry her teacher know about it cause every month, in the same date she always permission.."

7) Changes in psychological when care children with HIV, themes formed: fear, sadness, guilty
" scared if she has shorted life, even I know that only God who know about our life..(crying)"

" I often cried while I saw my child..why it happened to her.."

"..fell so guilty..eventhough I tried to let it go.."

8) Hope for children future. A theme formed: health, education and employment, child development".. I didn't expect too much, the important things that my grandson is healthy.."
" can walk normally.."
"..healthy, long age.."
"..get an education, get a job.."

9) Hope to health services . themes formed health education, privacy
" the position of this clinic is too open, public know about this clinic..sometimes I feel so shame to take my child here.."

" give us health education specially how to take care children with HIV.."

10) Experiences when give ARV to children, the themes formed: complaint and obidient
"..give ARV regularly but sometimes late, specials when he slept and hard to wake up..wait until he wake up.."

"..every day but sometimes late few hours ..specials when were outside, I must find privacy places where I can give ARV to my daughter.."

"im sure he didn't get ARV regularly cause his grandma work…that's wy I want my son stay with me..not with is grandma.."

"..yes sometimes I forget..and late.."

11) Preparing children to know their stratus, a themes formed: not ready and fear
"..my daughter was able to read..she is want to know about everything what she read.., in a clinic she read everything on the wall and asking about HIV…im afraid what will happen if she know about her status.."

" fear if he ask me..why??..i'm afraid he angry to me.."

"..the child has a right to know..but not now.."

12) The doble role: caring for herself and her children
"..yes I must focus of my own health and my child health.."

" ..im so worried, my CD4 only 14, I got syphilis, and im pregnancy now..must take care my child and he has walking impairment..its hard for me.."

13) Facing family conflict after the death of the parents..
"..my son always health before married with her..i know she is bad women, always change sexual partner,,so I don't want my grandson carried by her.., you know.. his grandma give him attention cause he got support from LSM..she only want the money.."

"..his grandma cannot caring him cause she is working everyday…, I want he is here..we can give him attention, takecare of him…controlled ARV…im sure my daughter got HIV from her husband…. they married by accident.."

14) Given need of play for children , the themes formed: type of game and controlled the game
"..walking impairment so he is playing by crawling.."

"..she can play anything but must save for her.."

" I watch him everywhere he play…he is so happy can playing with is friend.."

" I give her information.. when she play and get bleeding, she must clean it by herself in a bath room..she can play

everything and everytime..but it must safe for her and her friend too.."

DISCUSSION

1) Response of HIV diagnosis; themes formed: sad, denial
   The response of HIV diagnosis are denial and sad. This is a response when individuals experience a loss of (health). Lubkin and Larsen (2006) stated that it is important to remember and it is known that a person diagnosed with a chronic illness showed grief response. Some individuals may exhibit fear response because she will become dependent and can not live independently. This resulted in loss of the ability / power (powerlessness). Loss of this ability can cause grief response. Grieving is emotional response that people experience the loss of a loved object.
2) Response of children IV diagnosis: themes formed: sad
   In this phase, the reality has been realized, it can be expressed with sorrow or shame. Potter and Perry (2005) states that at the stage of depression, the reality has been realized, emotional reactions may be distancing themselves from social interaction and feeling lonely. Delaune and Lander (2002) states that individuals may also show an attitude like crying and did not talk much to the grief they experienced.
3) Complaints in treating children with HIV formed the theme of exhaustion, worry and financial health of the child
   Women with HIV AIDS cause various physical changes such as weakness or tiredness. This weakness is further increased with the dual role of mother, wife and himself who must care for their children and illness conditions. This leads to limitations in performing these roles are expressed by respondents to complain fatique with various roles to be run. According to Jackson (1999) changed the role of women with HIV/AIDS is limited role in childcare
4) Efforts are underway to handle the complaints, the theme of which is formed; pray, support costs and break
   Respondents noted an increase in terms of worship which is indicated by the closer to God and more diligent in doing worship. Spiritual is a key element of hope and desire. Other efforts are rest enough rest is relax conditions which will help increase the production of endorphins that can help the immune system, this will increase the body's energy and metabolism (Putu Oka, et al, 2005). Social support is access to individuals, groups or institutions that can provide assistance in a difficult situation (Nursalam, 2007). (Norbeck, et.al, 1983 in Carvehaels, Benicio & Barros, 2005). According to Ryan and Austin (In Friedman, 2002) that there is adequate support relate the rates of death, will speed up the healing process.
5) Changes in parenting after a child is diagnosed with HIV, the theme of which formed further protect.
   Children with HIV / AIDS require physical health services for children with HIV are more susceptible to opportunistic infections due to weak immunity. In addition, from the psychological aspects also need attention. Children are society's negative stigma against them. On the other hand it is often children living without parents or with parents who are also infected with HIV. So that the children need more protection from physical risks, risks of psychological problems and the risk of transmission to others.
6) Openness status of children in the family and society; theme that forms open and not open.
   Open as ready with consequences that exist and some participants are not ready, for fear of stigma and discrimination that will occur in children. Including social support from the community is needed to increase the ability of himself and his health. But because it is still the emergence of HIV stigma of HIV especially among women and children, the shame arises when social contact it is not separated by the stigma.

Stigma is a negative trait that sticks to one's personal because of the influence of the environment (KBBI, 2001). Goffman in Tsao, 2008 stated that stigma is an attribute or a label that causes a person is not respected, considered to have stains and ignored. Conditions of HIV / AIDS especially in women and children are considered to have an embarrassing disease that will cause anxiety, they will consider themselves different from others, it will affect the individual.

Changes in psychological care for children with HIV, the theme of which is formed fear, sadness and guilt

Various health problems cause high mortality in clients with HIV / AIDS. Moreover, the age of children in growing process besides causing physical problem it can make developmental delay. Feel sad because a child is sick and experience of developmental delays in response to the loss of health status in children. Guilt arises because of transmitting HIV to the child.

7) Hope for the future of children, a themes formed: health, education and employment, child development

Hope is a multidimensional concept that brings peace when an individual gets disaster (Potter & Perry, 2005). Desperate conditions complained of by the taste down effect on expectations. Hope this gives strength and confidence for individuals health. Hope gives a new energy that encourages individuals motivated to improve reception it self.

8) Hopes to health care, theme formed: counseling

Counseling is a process of helping a person to be aware of personal reactions to the effects of behavior and the environment and help people establish the meaning of behavoir Counseling HIV / AIDS is a dialogue between person with health services, confidential allow the person to adjust to the problems they experienced, able to make decisions and act associated with HIV / AIDS experienced (Nursalam, 2007).

9) Experience when gives ARV drugs for children, a theme that formed are: compliance and constraints

Regularity in taking medication or drugs is very important because if the drug does not reach the optimal concentration will allow the development of resistance. Compliance is a term used to describe the behavior of the patient in the correct medication dosage, frequency and time. Compliance is correlated with success and ARVs are very effective when taken as directed. It is associated with drug resistance and viral load reduction

10) Preparing children to know their status, a theme formed are: fear and not ready

Fear arising from a sense of guilt has been transmitted to the children, and feared the child would be angry to the mother. Fear is defined as a feeling daunted (shudder) will be facing something disastrous (KBBI) Fear is an emotion the individual against any feelings of danger or threat associated with an external object that is recognized by the public as a dangerous object. Of the various expressions of the participants, who expressed fear is fear of the angry child when the mother knows who transmitted HIV to the child.

11) The double role of caring for self and children

Women are housewives who have a duty to serve her husband and child care. It is still upheld in Indonesian society. Women as homemakers are women who work in the productive household to defend husband rowed in married life. In women with HIV AIDS cause various physical changes such as weakness or tiredness. This weakness is further increased with the dual role of mother, wife and himself who must care for their children and illness conditions. According to Jackson (1999) changed the role of women with HIV / AIDS is limited role in childcare.

12) Dealing with family conflict after the death of parents

HIV transmission sometimes cause problems or conflicts in the family, many couples blame and anger towards

her partner who transmitted HIV. This can happen also in his extended family to blame the source of transmission of the wife / husband. When parents are absent or dead can be prolonged conflict and a major family conflict in the care of children. From the expression of respondents conflict that arises when a parent dies is a source of transmission and blaming each feel entitled to retain grandchildren. Conflicts occur due to a situation where the desire or the will of a different or opposite to one another, so that one or two are interrupted. This conflict will evolve and affect the child psychologically.

13) Giving children needs of play, a themes formed: the type of game, control the game Play is a natural way for children to express themselves unconscious conflict (Wong, 1991) Play is an activity undertaken for the pleasure of it without considering the end result (Hurlock, 1978). Play is an activity that can not be separated from the daily life of children as play with work in adults, which can reduce the stress children, the media is good for children to learn to communicate with their environment, adapt to the environment, learning about the world around her life, and it is important to improve the mental well-being and social development. Playing for children with HIV / AIDS should still be given attention only various aspects related to the type, severity and risk of transmission. Playing alone for children with HIV / AIDS aims to: 1) To continue the growth and normal development. 2) Expressing feelings, desires, fantasies and ideas. 3) To develop creativity and problem-solving skills, the game will stimulate the intellect, imagination and fantasy to create something like that on his mind. 4) Can adapt effectively to stress due to illness.

CONCLUSION AND RECOMMENDATION

Conclusion

Family who caring children with HIV/ AIDS have many problems such as: sadness, fear, guilty feeling, overprotective in parenting, giving ARV to children, readiness to open children status, caring children developmental disability, worries for education need of the children, fear that they don't have longer time to take care the children and facing big family problem after parents death.

Recommendation

Nurse can give information about caring children with HIV/AIDS, give the support to family to get VCT program, ARV supervision, motivation enhancement, child health, children need to learn and play, support family to join with PMTCT program to increase quality of life of the children and family.

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